

Response ID ANON-G8PY-2G27-A

Submitted to **Safe and Effective Staffing in Health and Social Care**

Submitted on **2017-06-29 10:46:28**

Equality consideration

17 Do you anticipate any of the proposed options outlined in this consultation will have a direct or indirect positive or negative impact on any protected equality characteristics?

Yes

Comments:

Down's Syndrome Scotland (DSS) is the only Scottish charity focused solely on the needs of people with Down's syndrome (Ds) and their family carers. We provide information, support and services for people with Ds, their families, carers and those with a professional interest. We also seek to improve public knowledge and understanding of Ds and to champion the rights of people with Ds.

DSS welcomes the proposals to introduce legislation regarding workforce planning. We are of the view that options outlined in this consultation would help improve the quality of lives of children and adults with Ds, and their families, across Scotland provided that implementation is truly monitored and action taken when agencies fail to comply. But we also believe that greater attention should be given to the issue of training to ensure that the proposed options actually have a positive impact on expectant/new parents and people with Ds. As outlined in the consultation the NHS Staff Governance Standards require that staff are 'appropriately trained and developed'. However our evidence shows that it is not always the case at present.

In March we published a new report Listen to me, I have a Voice highlighting the experiences of our members with healthcare services and professionals. Two of the issues dealt with in the report are relevant to this consultation.

Firstly parents/carers of children and adults with Ds commented on the terminology used by some healthcare professionals to refer to their children. Parents are hurt by the use of terms like 'he's' a Down's baby/kid'. Poor language not only shows disrespect towards people with Ds and their families, it can also have a profound effect on parents who speak about feeling sad, upset and isolated because of such attitudes. A Fairer Scotland for Disabled People states that 'by using positive and empowering words, we can change the way people see disability'. As a charity we encourage everyone, including all health and social care services, to practice "people first" language. A person with Down's syndrome is NOT a Down's child; they ARE a person with Down's syndrome.

Secondly some parents also chose to share their experience of ante/post-natal care with us. Most of their comments describe very poor attitudes from professionals (including Midwives, Health Visitors, Nurses and Consultants). From feeling pushed towards having a termination following a pre-natal diagnosis to being left alone after birth, parents shared their experiences of what can only be described as appalling behaviours towards expectant/new parents. This is an issue that our members often raise and urgent action is needed to ensure that all expectant and new parents can rely on outstanding support and care within maternity services.

Workforce planning is key to ensure safe and effective person-centred care. However the provision of high quality care also relies on staff being able to develop their skills and access training as and when required. Increasing staffing levels will do little to improve the care of our members if staff looking after patients with Ds and their families have limited knowledge of conditions like Ds.

About You

What is your name?

Name:

Rachel Le Noan

What is your email address?

Email:

Rachel@dsscotland.org.uk

Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Down's Syndrome Scotland

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact

you again in relation to this consultation exercise?

Yes

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Neither satisfied nor dissatisfied

Please enter comments here.:

For this consultation it worked fine as I only answered one question which I copied and pasted from word document due to previous experience of draft answers not being saved properly and all comments being lost.